

The Shared Decision-Making Continuum

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DURING THE 20TH CENTURY, MEDICAL DECISION MAKING shifted from a paternalistic approach to an autonomy-based standard in the United States. Now, in the 21st century, the pendulum is swinging back and the medical community and the public are increasingly embracing shared decision making. In many other parts of the world paternalism remained the primary approach, yet there is now a move toward shared decision making occurring internationally. This “meeting in the middle” has been spurred by the 2004 endorsement of shared decision making over either strict autonomy or physician-directed decision making by the leading critical care organizations in Europe and the United States.¹ Furthermore, the American Medical Association, the American College of Critical Care, and the American Academy of Pediatrics all advocate shared decision making.²⁻⁴

Most patients (the term *patient* in this article denotes either the patient or the patient’s agent or surrogate decision maker in cases of an incompetent patient) and family members prefer shared decision making over either strict autonomy or physician-directed decision making.^{1,5,6} Recent legislation in US states gives physicians greater control. For instance, the Texas Advance Directives Act of 1999 (Texas Health & Safety Code §166.046) specifies the process by which physicians can withdraw life-sustaining interventions over patient objection, and in 2009 California enacted similar legislation (California Probate Code §4736). Such studies and legislation demonstrate that the move away from a strict autonomy model is now widely accepted in the United States. In Europe and other parts of the world, the move away from paternalism toward shared decision making is also becoming accepted in medical and lay communities, and patients are increasingly being given greater control over their medical care.

Although shared decision making is becoming the new standard, it remains unclear exactly what “shared decision making” means. The model for shared decision making described herein is consistent with ethical principles and patient preferences and can be referred to as the “shared decision-making continuum” because shared decision making will necessarily take different forms in different situations.

Shared decision making does not mean the same thing in all cases and therefore can best be understood as a con-

tinuum (FIGURE). At one end is patient- or agent-driven decision making, at the opposite is physician-driven decision making, and in the middle are many possible approaches. Discussion of 5 points along the continuum illustrates some of the possible approaches.

In patient/agent-driven decision making (akin to strict autonomy), the physician presents all options and the patient makes his/her own choice. The physician provides expert knowledge only and makes no recommendations.

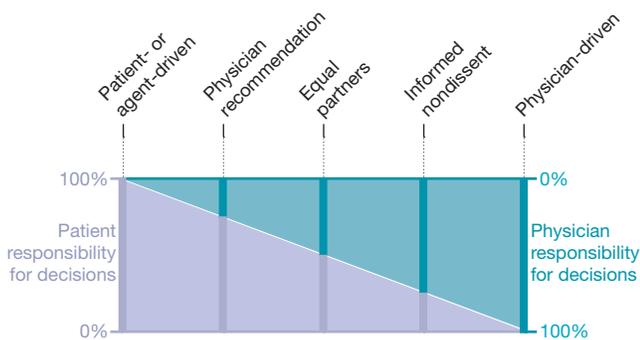
In physician recommendation decision making, the physician explains all options and also makes a recommendation. Because many decisions in health care are value laden, physicians must base their recommendations on the patient’s values rather than on their own. Ascertaining the patient’s values, however, often requires time and advanced communication skills. Furthermore, when a patient asks the physician what he/she would do, the physician must consider the patient’s perspective and ensure that he/she is neither intentionally nor unintentionally coercive.⁷

In equal partners decision making, the patient and physician work together to reach a mutual decision. This process often requires a longstanding relationship, and both parties must understand the values and biases of the other. Mutual respect and understanding are essential. Because the patient and physician necessarily have different perspectives, the physician must ensure that it is the patient’s values, not his/her own, that guide decision making.

In some cases it may be appropriate for the physician to bear the major burden of decision making.⁸ With informed nondissent decision making, the physician, guided by the patient’s values, determines the best course of action and fully informs the patient. The patient may either remain silent, thereby allowing the physician’s decision to stand, or veto the decision. In this approach the patient must understand all pertinent information (as he/she would in any method of decision making). Furthermore, the patient must appreciate that silence will be construed as tacit agreement. Patients must understand that they are welcome to veto the decision and if so, their wishes will be honored and they will receive excellent care.

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Figure. Shared Decision-Making Continuum

At the other extreme end of the continuum from patient/agent-driven decision making is physician-driven decision making. In general, physicians should independently make only those decisions that are value-neutral (eg, deciding what size endotracheal tube to use). Physicians must be extremely careful because patients may have strong feelings about seemingly value-neutral issues. For example, a child may wish to have an intravenous line placed in the right hand because the intensive care unit allows parents to sit only on the left side of the bed (due to equipment placement) and the patient wishes to have her left hand free to hold her mother's hand. Similarly, a patient may prefer a conventional ventilation mode even when high-frequency ventilation could provide greater lung protection because conventional ventilation requires less sedation, and being able to interact with family members is paramount. As such, when making what appear to be value-neutral decisions physicians should be aware of possible patient preferences and include patients in decision making whenever appropriate.

Patient preferences must guide the approach used, and physicians must appreciate that each patient is different and may have different preferences at different times and for different types of decisions. Some physicians may tend to use only certain decision-making approaches for specific types of decisions; however, patient preferences for decision-making approaches vary widely regardless of the type of decision being considered. For example, some physicians tend to use the patient/agent-directed approach for end-of-life decisions; however, even in end-of-life decision making when decisions require value judgments, many patients simply want the physician to decide.^{9,10} The types of decisions that call for different approaches cannot be categorized because each patient is different and it is the patient, not the decision under consideration, that guides the process.

Particularly in end-of-life decision making, some physicians may be uncomfortable allowing patients to abdicate decisional authority. However, there is no ethical reason to disallow this form of decision making when doing so is con-

sistent with the patient's preferences and the physician is making decisions based on understanding the patient's values and assessment of the patient's best interest. This does not mean that the physician is obligated to assume the role of decision maker. If the physician is uncomfortable in this role, he/she may decline to serve in this capacity.

While this approach to decision making has focused on the physician-patient dyad, an experienced clinician can include others (eg, family members, friends, allied health professionals) in the decision-making team. Expanding from the dyad to the team approach requires experience and excellent communication skills. Furthermore, all team members should understand the process and goals and appreciate the primacy of the patient's values.

The goal of shared decision making is to make decisions in a manner consistent with the patient's wishes. The patient drives the process. Determining where on the shared decision-making continuum the patient feels most comfortable requires clear communication and dedicated time. Shared decision making is often facilitated by a long-standing relationship between the physician and patient, although such a relationship is not compulsory.¹⁰ Active listening skills are essential so that the physician does not inappropriately take too much control nor force patients to bear more of the burden than they wish. Future work should assess patient satisfaction with the shared decision-making process.

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